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ABSTRACT

Project ESPIRIT (Educational System in Parenting for the Retarded with Infants and Toddlers) has provided home based services to 25 at risk children of mentaly retarded parents. Assessments performed at home are followed by development of individualized educational programs for both child and parent. Suggestions are given for establishing such a program to serve mentally retarded parents. Addressed are issues in child eligibility, staff recruitment and qualifications (such as 3 years' experience working with mentally retarded adults, experience with infants, and an ability to refrain from judging another's lifestyle based on middle class values), coordinaton of support services, and development of products. (CL)

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Replication of a Home-Based Prevention Project For At-Risk Infants Whose Parents Are Mentally Retarded: Development and Implementation

by

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In spite of their parents love and good intentions, the vast majority of normal infants born to parents who are mentally retarded will be developmentally delayed by age three. Their disability may occur because their mothers are unaware that parenting entails more than feeding, changing diapers, and keeping the baby clean. The cycle of functional retardation - which has its origins in an impoverished learning environment - will continue.

Project ESPRIT seeks to break this cycle. ESPRIT, an Educational System in Parenting for the Retarded with Infants and Toddlers, provides 4 day per week, home-based, direct service to at-risk children of mentally retarded parents. The ultimate goal of ESPRIT is to have all of these at-risk children enter preschool at age 3 with their developmentally normal peers.

Twenty-five children receive ESPRIT's services. Ages range from birth to 3 years. Approximately half the children are from single parent families. All families are economically disadvantaged. Intellectual capacity of the mothers ranges from moderate to mild retardation, and approximately half have other children.

Since ESPRIT is a home-based Program, an ESPRIT home visitor assesses every child and parent to determine the child's developmental level and the mother's strengths and weaknesses in parenting and daily living skills. When the assessment is completed, individualized educational plans are developed for both child and parent. So the child will remain on task developmentally. And the parent will learn the appropriate parenting skills.

Specifically, each child is assessed and monitored in the following areas: gross motor, fine motor, cognitive, language, social/emotional, and self-help skills. Based on this assessment, ESPRIT staff develops 6 month goals and objectives for both the child and the parent. Then, staff implements weekly program plans to achieve the long-range goals and objectives. Quarterly evaluations are designed to monitor the child's progress.

In addition, the ESPRIT social worker assists families in receiving other important community social services, especially health care, financial, and housing assistance.

In July 1979,Project ESPRIT was funded as a national demonstration program by the Handicapped Children's Early Education Program and ARC/Allegheny County Chapter.

ESPRIT is one of the few programs of its type in the country. It is our hope that there will be other programs like it in the near future.

The concept of providing services to at risk infants and their parents who are mentally retarded has been strongly supported in Allegheny County, PA where Project ESPRIT is based.

Outside of our immediate area, reaction to the program has been favorable and supportive. Because projects of this type are needed in other communities as well, people usually ask how to start them.

The purpose of this short presentation is to explain how it's done. The presentation will include the establishment of the program, the recruitment of staff, coordination of services, development of products and implications for replication.

Establishing the Program

We doubt that the community in which you work has a comprehensive program serving both mentally retarded parents and their children. However, we are certain that if you were to contact organizations that provide services to mentally retarded adults, you will find that some of these individuals are parents.

There are two basic reasons that justify the establishment of a program like ESPRIT. First, this special population does exist and needs comprehensive services. Secondly, other social services would be most happy to see these

client families in a program that is specifically designed to meet their needs, rather than providing piecemeal or ineffective service.

In order to establish your program, your first order of business will be to provide public awareness that the program does exist and has established specific eligibility requirements. The eligibility criteria of Project ESPRIT are the following:

1. A primary diagnosis of mental retardation for the parent.
2. Referral of the mother prenatally, or of the child up to 14 months of age.
3. The child must be intellectually normal at birth.
4. The family must be economically disadvantaged.
5. The mother must have problems of adaptive functioning that will negatively influence the psycho-social environment of the child.

Even if you are led to believe that there are not many individuals who fit the eligibility requirements, with a major effort devoted to publicizing the program these clients will be referred. Project ESPRIT started in July 1979, funded to accept 15 families. As of March 1981, we have had one hundred and ten families referred to us - all in the greater Pittsburgh area.

Recruitment of Staff

Since this program model is designed to be home-based, your direct service staff will spend 80% of their time in the field, in a situation that is filled with frustration and crisis. I would like to preface the following section by stating that for Metroploital Pittsburgh, the criteria determined for our staff has best met the goal of effectively teaching parenting skills. Perhaps in your own community, your requirements will differ.

The model home visitor should be a woman with an undergraduate degree in education who has had three years experience working with mentally retarded adults in a Community Living Arrangement or vocational setting, who has a

great deal of familiarity with infants, preferably from the experience of raising her own children, who does not judge another person's lifestyle based on middle class standards, who has a car in good repair, and needs minimal supervision.

Although your first reaction may be that we are describing an employee in a rather sexist and idealized fashion, let me explain our rationale for each prerequisite, based on our field experience.

Seventy-eight percent of the mothers served during the first project year, were either married to, living with, or involved with the father of the infant. In many cases the father is present during the hour long daily visit. The child's father has a strong influence on how well and how consistently the activities which the home visitor presents to the mother are carried out. In at least eighty percent of these relationships the male/female interaction is one of female dependence; that is the child's mother is heavily invested in meeting the needs of her mate. The father does not feel that his position of authority in the family is being undermined or usurped by having a woman teacher enter his home. He does not feel threatened when a woman is teaching the expectant or new mother how to nurse her child, or instructing the mother in the area of personal hygiene. Although we have not tested it, we contend that a female employed as the home visitor is more likely to succeed in carrying out the goals of the program.

An Undergraduate Degree in Education

While providing an educational model of cognitive stimulation, nutrition, health and safety procedures in the home is essential, a portion of the prevention which occurs is of a social service nature. Without exception, each of the twenty-five families enrolled in ESPRIT have enough social problems to justify a large portion of direct service time being applied to remediating these problems. However, the ultimale goal of ESPRIT is to insure the normal

development of the infant, so that he or she will enter a preschool for children who are not developmentally delayed. This educational goal is attained through teaching the adult to use parenting skills effectively. The home visitor whose background is in education is more likely to approach her client's programming from an educational perspective due to her ability to develop I.E.P.'s, her knowledge of instructional strategies and techniques, as well as an overall orientation to the importance of educational programming.

However, the project staff is aware that the problems of a social nature cannot be minimized or left unattended. These problems are identified by the home visitor who suggests a mehtod of remediation but does not utilize her time actually carrying out the activities for remediation. Except in rare instances, that responsibility falls directly to the project social worker.

Three Years Experience Working with Mentally Retarded Adults.

This requirement is almost self-explanatory. A person who sets unrealistic expectations for her clients and cannot meet these expectations in a brief amount of time, will burn out, and the client will experience failure. Those individuals who have had extensive experience in the field understand that goals and time-lines for completion of goals must be realistic, based on the functioning level of the client. Teaching in the context of realistic expectations reinforces the client to work towards both her and her child's next goal with enthusiasm.

A Great Deal of Familiarity with Infants, Preferably From the Experience of Raising Her Own Children.

From our recruitment efforts, there seems to be few individuals who have a degree in education as well as clinical experience with infants. It is extremely important for the home visitor to feel comfortable handling infants, and for her to be knowledgeable of developmental milestones. It is true that some of this information can be gained in a pre-service training

component, but the confidence which occurs from being a primary caretaker of an infant cannot be duplicated in a training module for this program. In addition, we have found that the credibility of the home visitor is heightened considerably when the client is aware that the home visitor is a mother as well.

Does Not Judge Another Person's Lifestyle Based on Middle Class Standards.

One of the components of our pre-service training program addresses the need of looking at the strengths of a family using an innovative approach. From a more middle-class value approach, these strengths might be seen only as needs. Without going into great detail, we will give you two examples. A mentally retarded mother sent her child to preschool with her lunch in a paper bag. The lunch consisted of an orange, cottage cheese and some raisins. However, none of the items were packaged separately - they were all combined together. A common reaction would be to say the mother does not adequately provide for her child. But the strength that the mother possesses in this example is that the lunch was balanced and nutritious. Another example is of a mother who was instructed to feed her newborn every four hours. She did not carry out the doctor's instructions and was considered resistant to suggestions from a professional. However, the mother could not tell time, and therefore, did not know when to feed her child. Identified as a need of this mother then, was a way in which to cue her for the time to feed. It was accomplished by identifying her television programs which were on at 6:00 a.m., 10:00 a.m., 2:00 p.m., etc.

Therefore, a shifting of perspective for the professional provides a creative method of client programming as well as building on the client's strengths and increasing her sense of success.

Needs Minimum Supervision

Those people who need a great deal of daily professional commeraderie, or who require a great deal of structure and immediate approval will not be effective as a home visitor in a home based program. Four days a week are spent entirely

in the field, with only one day set aside to be with one's co-workers planning weekly lessons and writing I.E.P.'s. Supervision occurs on a rotating basis, once every five weeks.

You may wonder why we have devoted a sizeable portion of time to delineate the prerequisites for an ideal home visitor. The reason is simple, to work with this population in their homes calls for an experienced, self-motivated, conscientious individual with a high tolerance for frustration. Home visitors are not easily replaced. When one quits, the resulting interruption of service necessitates that the new home visitor establish a new rapport with the family, and regain their trust. Timelines for the completion of goals may be delayed, and some skills that the parent had mastered will have to be retaught. Ultimately, an interruption of service delivery will impede the progress of both mother and child.

Coordination of Supportive Services

As we are speaking to you, we imagine you are mentally adapting this information to meet your specific organizational structure and your community needs or characteristics. Remember that when it comes to supportive social services, every community's resources are different. The following information is presented only in the context of what works for us in Allegheny County, specifically in the Metropolitan Pittsburgh area.

At the outset of the program, when we had no clients and hadn't even hired our full staff, we said that Project ESPRIT would be the primary caregiver to the client, and that all other home-based services such as Visiting Nurses, Homemakers, and Foster Grandparents would act as secondary support services. Where a duplication of services exsisted, the other agency's personnel would no longer provide service after the client entered our program. This decision, while being cost efficient, was primarily made for programmatic reasons. The mentally retarded adult who receives conflicting information from the Foster

Grandparent, the Visiting Nurse and various other social service personnel will become so confused that the agencies who are providing the services may, in effect, nullify the effect of the information presented.

Surprisingly enough, the other agencies agreed to our programmatic proposal. "Turfism" was not evidenced. We believe they were relieved that finally a program existed that would provide a great deal more intensive, individualized, and consistent intervention that they had been able to offer.

The policy which we have been able to informally institute is that, whenever possible, clients who are unable to use public transportation to travel to medical appointments will be transported by the staff from the Mother & Infant Care Program. All our client families receive WIC and are automatically given vouchers for ready to feed formula. Foster Grandparents and the Department of Public Welfare Homemakers do not provide services to our clients. In addition, when the Project ESPRIT social worker contacts the social service department of any area hospital and advocates on behalf of a client, the hospital personnel will comply with our suggestions because they have been alerted that our client is mentally retarded.

Perhaps our situation is unique, in that the cooperation we have received from other social agencies has been beneficial to us, and most importantly, to our clients. Hopefully, the coordination of services will be as smooth in your area.

Product Development

The impetus for the development of products for use with parents who are mentally retarded came out of basic necessity. To our knowledge, there were no assessments, and no programmatic tools available at the outset of Project ESPRIT.

Specifically, the entire staff collaborated on criterion-based assessments in the following areas: 1) the adult's parenting skills and 2) the level of

safety in the home as it pertained to infants and toddlers. An Independent Living Skills Criterion Based Assessment which addresses areas of functioning that immediately influence the child's environment has been developed as well. These assessment tools are available for distribution.

Once the staff had been trained, and was providing direct service, one overwhelming need for the majority of clients was determined. It was apparent that the mothers had great difficulty in carrying out the many daily activities which were required for the adequate care of an infant. In response, the ESPRIT Parenting Guide was developed. Please refer to your handout for an explanation of its use. This guide is presently available.

This past year, as our original group of project infants reached 2 and 3 years of age, behavior management became a primary area of concern. A guide for the professional who teaches behavior management techniques to mentally retarded parents is presently being developed, and will be available for distribution by June. Recently, a major undertaking has been the development of a manual describing the clinical model and procedures for the replication of Project ESPRIT. The publication date for the manual is July of this year.

Implications for Replication

The final aspect of implementation which we will address is what to expect once your program has been established, your staff hired and your caseload at capacity. We alluded to the fact that the home visitors must confront frustration and crisis as a matter of course. Unfortunately, many parents who are mentally retarded are overwhelmed by the responsibilities of the daily care of their child; that is, the medical appointments they must travel to, the added financial burden, and the fear that is expressed by many that their child will be removed if they are not "good parents".

It is a very slow process to explain to retarded parents the importance of regular clinic appointments for their child; that age appropriate nutrition is a primary factor in their child's development; that talking to an infant and

toddler is important whether or not the child is able to talk back; that infants cry for a variety of reasons, not because they want to annoy the parent; that it's normal for a child to assert his independence by saying no; that curiosity should be fostered, not inhibited; that they should pick up a crying baby and will not spoil the child by doing so, and that in the end, it is they and not the home visitor, who must be the teacher to their child.

The difficulties associated with providing direct service are complex and considerable. However, there is a bright side to this picture. We believe that mental retardation is not a factor in determining the phenomenon of bonding that is evidenced between mother and child. Our contention from the outset has been that parents who are mentally retarded wish to be good parents, but initially lack the knowledge and/or skills to do so. The intervention which the ESPRIT structure provides is for the mother to experience positive reinforcement from her child as she becomes knowledgeable of the child's developmental milestones. She receives pleasure as she observes her child reaching and passing these milestones due to her own interaction as the primary caregiver and teacher. And most importantly the child will have the opportunity to develop normally. After two years of development and implementation, our experience suggests that our original contention is sound.